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Citation for published version:

McNaney, R, Vines, J, Mercer, J, Mexter, L, Welsh, D & Young, T 2017, DemYouth: Co-Designing and Enacting Tools to Support Young People's Engagement with People with Dementia. in *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. CHI '17, ACM Association for Computing Machinery, New York, NY, USA, pp. 1313–1325, 2017 ACM SIGCHI Conference on Human Factors in Computing Systems, Denver, United States, 6/05/17. <https://doi.org/10.1145/3025453.3025558>

Digital Object Identifier (DOI):

[10.1145/3025453.3025558](https://doi.org/10.1145/3025453.3025558)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems

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DemYouth: Co-Designing and Enacting Tools to Support Young People's Engagement with People with Dementia

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ABSTRACT

There is a growing body of research examining the role of technology in supporting the care of—and relationships surrounding—people with dementia, yet little attention has been given to how this relates to younger family members. We conducted a qualitative study based on a series of 6 co-design workshops conducted with 14 young people who had personal experience with dementia. Initially, our workshops focused on understanding the difficulties that young people face when engaging, interacting and being with people with dementia. Initial analysis of workshop data informed the design of three digital tool concepts that were used as the basis for user enactment workshops. Our findings highlight the young people's desire to be more involved in their family discussions around dementia and a need for them to find new ways to connect with their loved ones with dementia. We offer a set of design considerations for future systems that support these needs and reflect on some of the complexities we faced around engaging young people in this difficult topic of discussion.

Author Keywords

Young people; Dementia; Co-design; Mobile Applications.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION

"Dementia doesn't just affect the person...it affects their whole social circle, their whole family, their whole world" (Jordan, 20)

It is estimated that there are approximately 46 million people living with dementia worldwide [35]. Dementia is an umbrella term which encompasses a range of conditions, with various symptoms, caused by a degeneration of neurons in the brain. It can affect activities of daily living (e.g. money management, cooking, washing, dressing) and cognitive functioning (e.g. memory, reasoning, planning) [4], and can

cause fluctuations in, often challenging, behavior. Communication can be especially effected, encompassing difficulties with the expression and comprehension of spoken and written language [38]. Issues range from simple word finding difficulties (such as forgetting the names for people or things) to becoming completely non-verbal in later stages [49]. Unsurprisingly, communication difficulties can equally have a negative influence on relationships between people with dementia and loved ones [10,29,34,38,40,49].

Communicative engagement is vitally important to the quality of life of people with dementia and those around them, but becomes more difficult as the condition develops. This often results in social withdrawal and isolation of people with dementia, and a strain on relationships between family members [52]. There are resources available to help people learn skills and strategies to effectively communicate with their loved ones [e.g. 2,3,53]. However, there has been little study of how intergenerational engagement—between young people and people with dementia—might be meaningfully supported. This is despite estimates that around 250,000 youths in the USA help to provide care for someone with dementia [31]. This brings to light the need for resources to help youths make sense of the multi-faceted, often transient, changes that might be occurring in their loved one.

In this paper we describe work conducted in collaboration with Youth Focus North East (YFNE), a regional charity that supports youths in having a voice within local communities. A key feature of YFNE's work has been in contexts related to youth engagement in health and care services, with a strong focus on supporting those with care responsibilities. Our initial engagement with YFNE involved working together to gather informal feedback from youths on an online toolkit [53] that provides information around strategies for interacting with people with dementia. However, preliminary discussion suggested the advice offered did not always map on to the youths' experiences, highlighting a need to better understand how young people experience this complex condition.

In this paper we describe 6 iterative co-design workshops conducted with 14 youths with personal experiences of dementia. These started by broadly exploring participants' experiences of dementia, identifying common issues to be



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CHI 2017, May 06–11, 2017, Denver, CO, USA
ACM978-1-4503-4655-9/17/05.
<http://dx.doi.org/10.1145/3025453.3025558>

addressed, then generating, refining and finally enacting a number of concepts for new digital tools and services to support youths' engagement with people with dementia. We contribute; 1) new insight into how youths currently engage with dementia, from both a personal and wider family viewpoint; 2) the complexities of designing with this diverse group, particularly in engaging them in sensitive topics; 3) design considerations relating to the development of technologies to support youths be more connected with loved-ones with dementia and enhancing their ongoing care engagement. In providing these contributions our intention is not to present finalized technology designs; rather, we highlight how our co-design techniques elicited empirical insights around the young people's articulated experiences of dementia and the challenges they face, and how these can act as a foundation for future technology design.

BACKGROUND AND RELATED WORK

Youths and dementia care

The United Nations define youths as people between the ages of 15 and 25 [44]. Those with care responsibilities may offer practical or emotional care, conducted alone or in support of primary care responsibilities of another adult [11]. Young carers are less likely to spend as much time in education as their non-caring peers [24], which can negatively impact their academic achievements, social life and the type of employment available to them.

There has been growing interest within the field of HCI over the past decade around the design of technologies for people with dementia to support their care. As a result, an abundance of work has emerged focusing on designing with people with dementia and their adult caregivers [e.g. 5,7,26,27,28,47,48]. This prior work has offered deepened understandings of how to sensitively design with people with dementia and their caregivers, with insight ranging from supporting functional care needs within the family unit (such as wandering [26] and meal times [39]) to enhancing personhood [48]. However, there has been little work setting out to understand how younger family members might be supported as part of the care ecology of older family members with dementia. This is representative of wider concerns that there is a dearth of knowledge on how youths experience dementia in their lives [37].

Engaging youths in discussions around health

It has been noted how youths experience desires for independence and autonomy as they begin to negotiate their individual and social identities. Erikson's seminal work presents a theoretical perspective on the key stages of psychosocial development throughout the life course [13]. He describes how adolescence is pivotal to the formation of identity, as youths begin to explore their belief systems, their personal values and extrapolate their current life experiences (e.g. their studies and friendship groups) onto their future life goals. Over the past decade, as technology and social media use have grown, youths have increasingly been using online platforms to negotiate their identities, blurring the

boundaries between their public and private, real and virtual world experiences [18].

Within the field of HCI, youths remain a relatively under-represented group [15,16,17,20,23,32,36,45], particularly in terms of their involvement in design. The complexities of involving youths in design work have been discussed [15,17,45], especially as it relates to the experience of transition between childhood and adulthood. There is an emerging literature around the needs and values of youths in the context of designing personalized health systems [e.g. 20,23,45]. But, there remains little understanding around how we might support them in navigating complexities that arise when changes in their family occur.

Intergenerational communication

While there is limited work that focuses explicitly on the lives of youths in this context, there has been research exploring intergenerational engagement for the purposes of building technology mediated links between older adults and young people. A portion of this work has looked engaging older people in supporting the education of youths [12,18,13], such as the ongoing 'School in the Cloud' project in which retired teachers are supporting learning in rural India over Skype [12]. There has also been work investigating the use of technology to mediate playful interaction between grandparents and their grandchildren who live apart [45].

Another theme within the literature is the use of video based experience sharing as a means to facilitate intergenerational communication [6,30]. For example, Bentley et al [6] describe the 'family stories system', a location based video sharing tool which allows senior family members to record video memories (at home), inspired by specific places, and pin them to a location on a map. Younger family members would then serendipitously be played these stories when in the surrounding area. Although this work was asynchronous in nature, the authors found that use of the system facilitated a sense of connection from younger participants as they learned about their grandparents' lives. It also prompted increased communication between families as they inquired about, and engaged in, the stories been told.

Given that reminiscence is one of the most widely used psychosocial interventions in dementia care, with reported benefits to mood, well-being and quality of life [51], there are certainly applications for this type of technology mediated experience sharing. However, most previous work has focused on cognitively able older people, or adult carers. As such, there remains a gap in the literature around how we might support intergenerational communication between people with dementia and youths. In addition, prior research on the creation of information and support packages for carers and family members of people with dementia has highlighted the need to adapt such resources for younger audiences [52]. In the following we describe our study, which aimed to address this gap by working directly with youths to understand their relationships and engagements

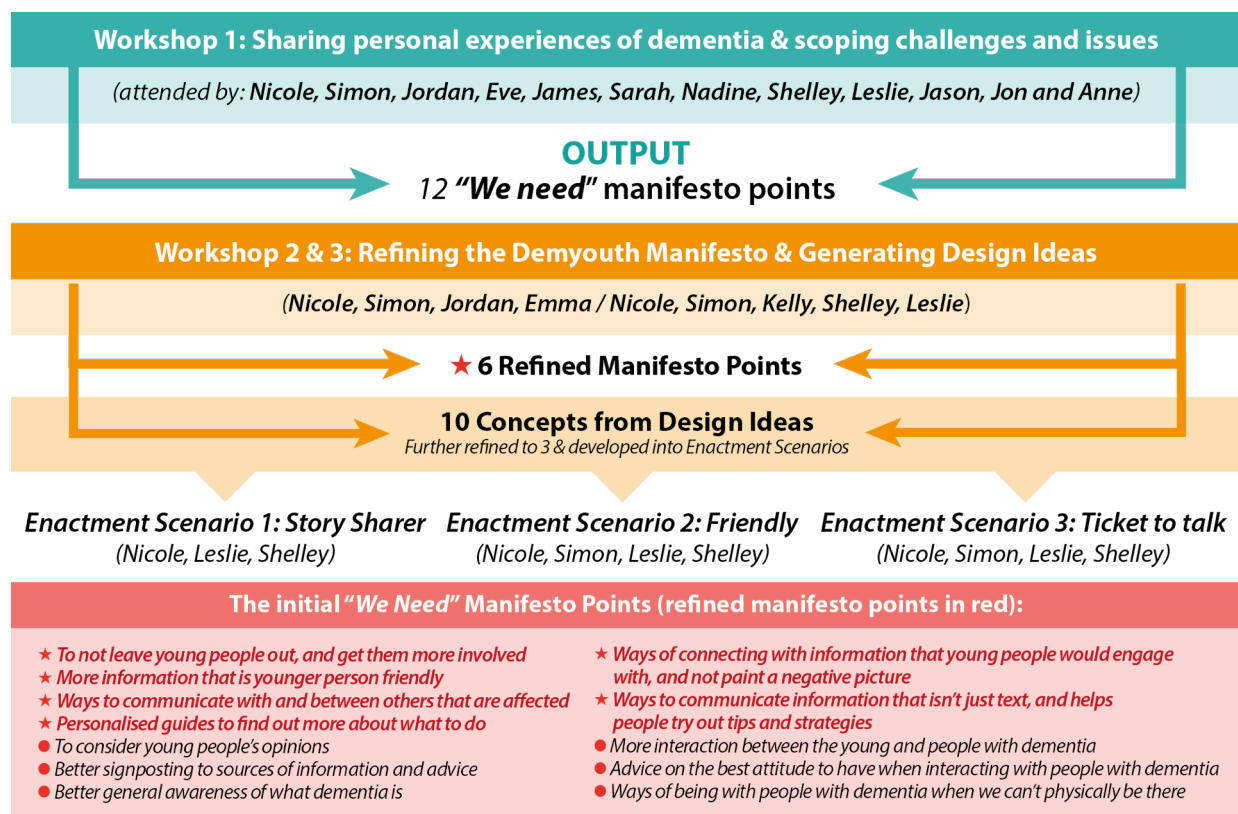


Figure 1. Diagrammatic overview of the DemYouth co-design process.

with people with dementia and the issues, if any, they face within these.

STUDY DESIGN

We approached the research with a view to understanding the care roles that youths were currently undertaking around dementia. In referring to care, we define this broadly; including a grandchild providing company and conversation to a grandparent, a youth who regularly looks after an older family member, or a youth engaging in formal care responsibilities within a care home. Throughout the research we attempted to avoid medicalizing dementia, instead focusing on the youths’ experiences of the condition and how they were living with the challenges it brought about. In doing so, we aimed to explore the potential for technology to support youths in engaging meaningfully with people with dementia, through a process of co-designing ideas based on identified challenges and issues.

Participants

A total of 14 youths (9 female) took part in the research. All were involved with YFNE, who facilitated the identification and recruitment of participants, and were aged between 16 and 24. Participants represented a diverse set of experiences and circumstances that motivated them to take part. Nine had family members, primarily grandparents, with dementia who they saw regularly. Two participants (Jordan and Emma) were volunteering in care homes for a day a week, conversing and interacting with residents with dementia. Finally, Nadine, James and Leslie had ongoing care

responsibilities for family members with dementia. These participants dedicated significant periods of time each day to caring for their older family members. For 2 of these participants this had involved having to withdraw from upper high school and college education.

Workshop structure

Our co-design activities were conducted across six design workshops. Workshops were divided into two stages of activity. Stage one (workshops 1-3) was focused on broadly exploring personal experiences of dementia and identifying specific issues and challenges to be addressed. Stage two (workshops 4-6) involved an in-depth exploration of three design concepts that were created through a comparative analysis of ideas and discussions from stage one. An overview of the workshop process is provided in Figure 1. The workshops were iterative in nature, with explorations at each stage being drawn from ideas in the last. Workshops lasted approximately 2-2.5 hours each and were held in evenings or at weekends, to accommodate the youths.

All participants were invited to all workshops. However, due to competing schedules (related to school and college work) and care duties, they were not all available for each session. Because of this, the start of each workshop provided a recap of what happened at the previous workshop, which aided reflection and discussion for both those who did and did not attend the previous engagement.



Figure 2. Participants engaging in the design idea generation activity from Workshop 3.

Analysis of the data

Each workshop was audio recorded and transcribed verbatim. Two members of the research team conducted an inductive thematic analysis on the transcripts [9]. Data was summarized with short one or two word codes, at the sentence-to-paragraph level. Codes were compared and contrasted to one-another, then grouped together, which led to the construction of themes that captured the core topics and concerns coming from the data. Analysis of the data was conducted following individual workshops, to inform the design of following workshops, and at the end of each stage. For stage one, this was to inform the refinement of proposed ideas into concepts, and for stage two to understand the responses to, and engagement with, the design concepts that had been created, and to derive considerations for the discussion of our work.

STAGE 1: SCOPING, EXPLORING & DEFINING

In the first stage, we ran three workshops that went through phases of scoping and exploring personal perceptions and experiences of dementia, and then defining specific issues and challenges to be addressed in the project. Figure 1 visualizes the workshop structure across stages 1 and 2.

Workshop 1 (n=12) opened with ice-breaker activities that enabled the young people to introduce themselves and get to know one-another. Following this, we facilitated a series of short activities designed to stimulate talk among participants in relation to perceptions of dementia, with a view to drawing out participants' personal experiences of the condition. The workshop concluded with the creation of a set of 12 "we need" points (see figure 1). These were intended to represent a set of problems, ideas and challenges that the participants felt were important for engaging youths in issues relating to dementia. These 12 points acted as a "manifesto" for the project going forward.

Workshops 2 (n=4) and *3* (n=5) focused on refining and prioritizing manifesto points from workshop 1. Participants were split into groups of two or three and asked to discuss, and then rank, the 12 manifesto points in order of significance. After this, they were invited to choose the three

manifesto points they felt were most important to take forward. We brought the small groups together to compare their selected priorities; again, after a short discussion participants were asked to refine these into three collective manifesto points. Throughout these activities, participants were given opportunity to combine, refine or edit manifesto points to represent their discussions.

Having selected a set three manifesto points, participants were invited to begin exploring opportunities for designing around these three issues. To scaffold this activity, we introduced the notion of personas to participants. While personas are simplistic, our intention was to engage participants in further reflection on how their selected manifesto points related to either their own personal experiences, or the experiences of other youths and their families. Using a provided template, participants created a persona that, to them, represented people experiencing the types of challenges they identified as priorities in the first activity (e.g. a young person who was struggling to cope with instances where their grandparent forgot who they were). These were then presented to each other, identifying commonalities and differences between the different personas. Finally, we provided a set of ten cards that depicted features and qualities of a combination of well-known, and more obscure, digital services (e.g. a website allowing curation of online material into personalized groups; an app allowing private messaging to specific groups of friends; location based app allowing viewing and posting of anonymous messages to those nearby). Participants worked in small groups to discuss each of these cards. Following this, they individually generated design ideas that combined up to three of the cards and responded to the identified needs of the personas created earlier (see figure 2). The workshops closed with participants sharing their created ideas, elaborating on how the ideas related to the personas and the manifesto points underpinning them.

Findings from stage 1

Trust, fear and confidence

When discussing their experiences of dementia, the youths highlighted the wider impact that it had, not only on them and their relationships with their loved one, but also on the family unit. Where a grandparent was previously seen as someone they were allowed to spend time with, concerns about their perceived abilities as their dementia symptoms gradually progressed was often seen to make parents fearful of letting their children spend time with them alone. For example, Nicole described: *"I've seen a lack of trust leaving kids with my Granddad...when there's a lack of trust from a parent or another relative then the illness has taken away that bond and that's slightly more detrimental than the illness sometimes"*. The youths widely discussed how this fear from parents caused them to become 'left out' of the discussions about, and experiences with, their grandparent. For many, this was a key issue they wanted to address: *"[it should be the family] not saying, 'We'll protect the children and keep them out of it' but actually, 'Yes, your Granddad's starting to forget things but when he's a bit cross*

it's mostly because he's frustrated because he can't remember. It doesn't mean he doesn't love you." (Kelly). However, it was not simply the fear of the person with dementia's ability that was seen to cause relationship breakdowns within the family unit. The youths also felt that their parents had self-doubts around their own abilities to cope with dementia, which in itself caused them to feel a loss of confidence when trying to explain the situation to young family members: *"if the parents are more confident in responding to the condition then they'd be more confident in supporting younger people."* (Kelly). Simon described how upsetting he found it to see his family become frustrated with his great-grandmother *"it's horrible to see everyone getting frustrated with her"*, where Leslie explained how she often took on the role of helping her family members to understand dementia: *"A lot of people, because they don't understand it, think the person is always going to be like that [violent]. It's basically just trying to give information proving that isn't always going to the case."*

A further issue related to fear and confidence identified by participants was a general observation that *"you don't see people with dementia out and about much"* (James). There was, for some, a question about whether they could take their grandparents to public places and spaces. This was often framed in relation to personal experiences of family members—like aunts, uncles and parents—inferring that, with dementia, comes an inability to leave the home: *"they don't really want her to go out, just in case something happens"* (Nadine). Leslie further described how she felt her family's unwillingness to engage with her grandmother's dementia had led to her becoming isolated and less independent:

"She's in a home at the minute and the family have just sort of forgot about her... She still remembers about the day centre she used to go to and still talks about going there [...] She just stays in her little independent flat because she doesn't like going downstairs, so it's kind of taken away her independence really"

Participants felt that youths were often infantilised by family members when it came to discussing dementia, often due to adults' own fears or lack of understanding. However, they represented themselves throughout the project as strong advocates for their loved ones with dementia, expressing desire to support them to remain independent.

Talking, communicating and relating

There was much discussion around how communication breakdowns between family members and the person with dementia caused frustrations and loss of confidence. Simon described how this led to his family disconnecting from his grandmother altogether: *"everyone was really frustrated [...] it got to a point where no one went to visit her or anything, apart from my granddad [...] he could talk to her all day really"*. Nicole explained how in her family there was often an onus on one person to be the main communicator: *"you may have one person who can communicate really well but if others can't communicate then it is reliant on that one person to do it all"*. For Emma, it was her younger cousins who struggled with visiting her Grandmother: *"they never really know what to say anymore [...] they go because they feel like they should go and see my Nana but they don't really know what to do [...] It's quite hard"*.

This was echoed by Kelly: *"I find it quite heart-breaking to visit him [her grandfather] because I just feel so bad for how confused he is. So it makes it a lot harder because there are very few ways in which we can connect anymore"*.

All of the youths, in different ways, highlighted how they sought to find new ways of connecting with their loved ones with dementia. Discussion highlighted a need to find ways to start conversations: *"Like a safe prompt to get things going when it first becomes more daunting"* (Emma). Participants discussed, at length, the concept of using a mobile application to curate information, relevant to the person with dementia, to help initiate talk: *"it will be much easier for [youths] to have a conversation [if] they talk about things that were interesting for their grandparents"* (Emma). Refining this idea further, the youths suggested the use of different media, such as photographs and songs, as well as having a way to inspire different methods that they could use to encourage engagement with their loved one:

"if the app had somewhere where you could tap for inspiration [...] if you're at a loss then you've got something like, 'Write them a letter about something you've done in the past' or, 'Ask them about Uni', or something like that." (Kelly)

They also described how ideas such as this might act as a way to connect with other family members, who could then subsequently use the content to find new ways to connect with their loved ones by exploring their lives: *So they will get their profile to begin with, originally and then they would branch off with their family member...And then the person will be able to access them to have a look at their life together"* (Simon). This concept of exploring the life course and connecting with people with dementia on a deeper level was seen as important for supporting *"meaningful conversation"* (Emma) about *"something they were able to relate to"* (Simon). This was linked to the idea of seeing the positive in people with dementia: *"reliving the good memories that they are remembering"* (Leslie) and *"not being afraid of them just because of the illness that they've got"* (Shelley). Critically, it was not that participants felt that they needed to, or wished to, learn the *"rules to follow"* (Nicole) when talking to someone with dementia; rather it was that they needed resources to support them in initiating conversation in the first place.

Informing, understanding and personalizing

A further set of issues identified in the workshops related to how the available resources surrounding dementia were inaccessible to youths. Participants described how sifting through multiple web pages was often felt to be overwhelming: *"I have realized that there is so much out there. There is some good information out there, there is good advice, there is good stuff but it is so overwhelming for someone in that situation"* (Jordan). They noted that much of the 'good' information is often very difficult to find: *"Google is good if someone else has searched it before you, if no one else is thinking the same thing you'll not get anything"* (Nicole). Suggestions arose around the use of different media to create more 'young person friendly' information: *"sometimes you don't want to read a load of text sometimes you just want to watch a video or listen to an audio book or whatever"* (Jordan). Nicole also suggested

using playful methods: *“Like making a cartoon or a game to mix the information together”*.

The youths described how available information appeared to be highly generic, impersonal and difficult to relate to their own experiences. Initial discussion centered on *“everyone’s situation being different”* (Simon) and how *“you can have happy people, sad people, and people with a whole range of different memories”* (Leslie). Nicole for example, reflected on difficulties she faced when trying to relate information she found online to practice: *“it’s totally generic [...] If you are just going to visit a relative with dementia you want to know some advice on how to speak or deal with that relative”* (Nicole). Simon reflected on his personal experiences of *“being thrown in the deep end”* several years ago when he visited his Grandma soon after she was diagnosed with dementia. He noted that *“there was no information for me out there”*, and that he wouldn’t really know *“what to search for”*. One thing that did help was writing notes about the things that seemed to lead to good conversations with his Grandma. From this, he suggested: *“nothing electronic but a pocket guide [...] They wouldn’t need to carry it round with them, perhaps they could put it in their grandma’s biscuit tin or whatever”*. While seemingly a little frivolous, the biscuit tin referred to being able to *“hide it”* but *“know where it is when you need it [...] all kids know where the biscuit tin is!”* (Simon).

This discussion highlighted both the desire from the youths to learn more about dementia, and a need for accessible information that would support them to do so. They felt there were several barriers to their access to information: not having the correct language to search for information, being unable/ unwilling to negotiate large amounts of information, and not knowing what online information to trust. While they realized there was a growing wealth of information for them to draw on, they found it difficult to connect with and, most critically, to use in practice.

Sharing, relating and experiencing

It was clear from participants that our workshops provided a very rare opportunity for them to discuss and talk about dementia. There was a recognition that they themselves had rarely discussed the condition with others: *“I think these workshops have been the first time I’ve chatted it about it really”* (Nicole); and *“Me and Nicole have known each other for years, but we didn’t know we both had this in common before we talked about seeing the [recruitment] advert.”* (Simon). Emma observed that whilst she talked to her cousins about their grandmother’s situation, none of them had really talked about it with friends. Leslie further reflected: *“It’s hard even when you’re caring for someone and you want to talk to others. Where do you go to find them?”*. While there was recognition that professional services did exist, it was felt these were more *“informational”* in nature, and instead there was a desire to seek engagements with people in similar circumstances: *“it’s nice to get professional opinion but...it can also be more beneficial to speak to your peers...because they are in the same position as you”* (Nicole).

Perhaps unsurprisingly, many of the participants invoked design ideas that brought the qualities of the workshop

environment to online platforms. For example, Nicole created an app that combined *“local chatter”* features with the ability to *“chat instantly”*—allowing her to *“message someone personally”* who lives nearby and is in similar circumstances. Sarah suggested a *“private social network”* that forced you to *“register an account [...] to stop trolls”* but then supports *“sharing your stories in an anonymous feature”*. Jordan simply suggested building an online *“community”*.

This process of peer experience sharing was seen as a somewhat cathartic release. Given the already discussed issues the youths described around seeing their parents struggle, peer support was deemed a useful resource for learning about dementia, through experience sharing and learning from one another’s mistakes in a supportive way.

STAGE 2: EVOLVING AND ENACTING CONCEPTS

Following our analysis of the initial three workshops, we entered a phase where design concepts were ideated around, and then evolved and refined. These were then used as the basis for a final series of enactments workshops.

Initial analysis provided a range of insights that acted as a starting point for further design. We first identified excerpts from participants where design ideas, or components and features of them, were explicitly articulated. We extracted a total of 23 design ideas, each anchored to data from stage 1. We iteratively filtered these down to 10 design concepts, by combining and refining the ideas that motivated them. This final set of concepts were then more fully realized by writing scenarios depicting the design-in-use, drawing on the language of participants. Through further discussion in design meetings amongst the team (researchers and staff from YFNE) three ideas were taken forward for further exploration with the youths. The final selected ideas were: 1) *StorySharer*: A platform allowing youths to share positive experiences of dementia, in the form of short video and audio clips, which are publically shared, to support advocacy and awareness; 2) *Friendly*: A rate and review platform for local establishments based on their ‘dementia friendliness’ related to community identified criteria, which can also be used as a learning and training tool for dementia awareness.; 3) *Ticket to Talk*: An application allowing the curation of media related to the life of the person with dementia. Different types of content can be collected and then used as a resource in conversations with the person with dementia.

Enacting DemYouth Design Concepts

We used our 3 selected design concepts as the basis for a further set of workshops with the youths. The design of our workshops was inspired by prior work on user enactments [32]. Odom et al. highlight how user enactments are a productive way of engaging participants in experiencing a snippet of what the future might be like and then engaging in reflection on existing situations, desires and practices in reference to this imagined future. In user enactments, design teams create the conditions for articulating aspects of *‘the physical form and the social context of simulated futures, and ask users to enact loosely scripted scenarios involving situations they are familiar with as well as novel technical interventions designed*

to address these situations’ [32] (p.338). Our approach to enactments deviated from this prior work in some key ways. First, we were less concerned with exploring the physical realization of our design concepts, but instead the ways in which these concepts might act as frameworks for youths to create, share and consume different forms of digital media related to dementia. Second, while the stage 1 workshops were highly insightful, we were still at a stage of exploring the social context surrounding intergenerational engagement and dementia. As such, we designed each of our enactment workshops to take participants through a series of structured scenarios that spoke to the qualities of the underlying design concepts. In doing so, we sought to use these enactments to further probe, elicit talk and reveal insights related to the issues and context we set out to understand and design for.

Enactment 1 (E1) – StorySharer: The first enactment workshop (n=3) revolved around the *StorySharer* design concept, imagined to be accessed on a mobile device. In the concept scenario it inferred people could share short ‘video-diaries’ or ‘vox-pops’ that can then be viewed, commented on and used by others. The *StorySharer* concept also guided users to identify friends, acquaintances and family members who they would capture ‘peer interviews’ with. As such, the concept explored two key issues from the earlier stages: i) issues around there being no platforms to share and hear other youths’ positive stories of dementia, and ii) engaging youths to make visible the hidden commonalities they have with many others in their age group in regards to dementia.

In E1 we took participants through structured activities that explored the potential production of media for *StorySharer*. We set them a brief, tasking them to collect stories from people they knew who had personal experiences of dementia. Initially, we asked them to generate, as a group, a series of questions they might use to structure a discussion. After this, we asked them to physically map the network of people with whom they might want to share and receive stories about experiences relating to dementia. Each participant was given a set of flags that they could write names on and different colors of string which could be used to add ‘connections’. Next, we then asked the group to individually refine the questions that they would like to ask someone about dementia. Finally, everyone at the workshop (including the research team) ‘interviewed’ one-another for 3 minutes using the developed questions. The session ended with an open discussion on the activities, and reflections on the value of collecting stories around dementia.

Enactment 2 (E2) – Friendly: The second workshop (n=4) revolved around the *Friendly* design concept. This concept invited people to rate local places—such as cafés, restaurants and transport offices—for how accessible and enjoyable they might be for people with dementia. It was imagined that as people rated places, *Friendly* would prompt them with tips and advice about what to look for, educating both those who completed the ratings, and the establishments that were reviewed through its use. This concept thus explored two issues from the initial workshops: i) engaging youths in a

practical way to learn more about the condition; and ii) harnessing the sense of advocacy from the first workshops, focusing on what the person *can* do and ensuring they, their families and their carers can be visible and independent citizens.

In E2 we first asked the youths to define what they felt makes public and social spaces ‘dementia friendly’. We prompted them to think about elements related to signage; layout and design of the space; the people who were there; and the general ambience. They were asked to devise a set of 4 criteria for each element, by searching online and drawing from their own experiences, and enter these onto a set of review templates. We then provided them with a small budget to spend in the local town centre. The group were asked to, in pairs, visit a café (to buy a drink or snack), a transport hub (to navigate around and find travel times), a chain store and charity store (to purchase something) and finally a public place to rest (e.g. a street bench or seating area). Once they had returned with their completed reviews, they mapped the places they visited geographically, and discussed the potential dementia friendliness of the local places. Again, the workshop closed with an open and reflective discussion on the activities.

Enactment 3 (E3) – Ticket to Talk: The final workshop (n=4) explored the *Ticket to Talk* concept. The concept posed that a young family member would be guided through finding and collecting media related to a specific period of their loved one’s life. It posed that the user would provide basic information related to the person they wished to collect media for. From here, it would prompt them to find clips of songs, movies, TV shows, reports on cultural events and personal photographs from certain periods of time. These could then be used to initiate and guide conversation when meeting or visiting a loved one. This concept explored two issues from the initial workshops: i) it responded to issues relating to a lack of knowing ‘what’ to talk about with older family members; and ii) it provides a personalized way to document and reflect on what communication approaches were, or were not, working.

In E3, we first presented the youths with the persona of Agnes. Agnes was 74 year old lady with Alzheimer’s who they were visiting as volunteers. We posed that Agnes struggled to follow conversation, making seemingly unrelated comments about her brother’s visit, but settled in to happily watch a musical, singing along to the songs. We asked participants to identify sections of the scenario where communication breakdowns had occurred, and why they thought these may have happened. From here, we tasked them to create some ‘tickets to talk’ to bring to their next visit. For this they used media they found online (e.g. photos, YouTube videos, Wikipedia) and the small bits of information they knew of Agnes. Finally, we asked them to, in pairs, role play the scenario again (with the researchers playing Agnes), using the tickets that they had collected. As before, the workshop closed with an open discussion.

Reflections on the DemYouth Enactments

Problems with making things personal

During E1, we asked the youths to visualize the networks of people surrounding them with experience of dementia. They started to earnestly create labels for people; starting with themselves, they mapped out their family members including their loved one with dementia. However, very quickly each participant hesitated and struggled to add more. With some prompting they started to add other people they had met as part of the DemYouth project: *“oh, yes, and there’s Jordan, he worked in the care home”* (Nicole). They started to identify some links and connections between one-another: *“Jimmy [a youth worker] knows all of us”* (Leslie). However, upon completion, their networks were still rather small, primarily populated with people met from the project or charities in the local town.

It became clear from this activity that the youths had a distinct lack of close peers with whom they could connect with about dementia. Discussion highlighted how they were unable to engage in these types of discussions with their wider circle of friends: *“I don’t really know many friends who I could talk to, because I don’t really discuss [dementia] other than with Simon who said that his family had it”* (Nicole). Because the youths had simply not discussed dementia with friends, they knew of very few people with similar experiences, despite acknowledgement that the condition is *“all around us”* (Nicole). In addition, several participants expressed a reluctance to ‘open up’ about their experiences of dementia with people that they did not share a close bond with: *“I don’t like discussing my own personal issues and situations like that with people I don’t really know so it’s kind of hard for me to open up about the whole thing”* (Leslie).

In the question generating activity there was a similar reticence to ask personal questions due to concerns around the types of emotions that they might elicit. Reflecting on their own experiences in the early stages of the project they saw *“the benefits of talking to peers”* and the creation of *“private social networks”* to support these discussions. However, this exercise highlighted that, while they were more than happy to share advice and give support, they felt discussion of rich, personal experiences should be reserved for close ties: *“with a family member or something it’s more about sharing experiences but with a stranger it’s more about asking advice”* (Nicole). The youths felt more comfortable sharing the wealth of advice they had to offer, from signposting resources (e.g. websites and documentaries) and local services they found useful, to sharing small snippets of positivity that they felt would help others, such as: *“remember the person is still there”* (Nicole); and *“it’s still your family member at the end of the day”* (Leslie).

Too much unhelpful information

Reflective of earlier discussion around the ‘sea of information’ surrounding dementia, the youths found it difficult to make sense of online information around dementia friendly places in E2: *“we searched quite a lot of things but didn’t get many results. There was a lot of writing on there but not a lot of substance”* (Simon). They felt that much of the information that they did find was simple common sense,

and not much use to them: *“I think it was all common sense to be honest, we did find an interesting article on the [charity] website but it didn’t really lead to much”* (Simon). This activity showed how difficult it was for participants to use online resources to find out specific information about dementia. It also demonstrated a huge reliance on visual examples. For example, one group spent much of this activity looking at images, which made sense considering they were searching for inspiration surrounding physical layout. They only paid limited attention towards reading through long textual resources, and found it challenging to extract the information they wanted. Nicole noted much of the text was *“business speak”* and *“not for a normal person”*.

Despite this, participants managed to select a final set of criteria for rating local places. These related to the physical layout of the establishment (e.g. easy access to a disabled bathroom); how appropriate the atmosphere was (e.g. volume of ambient noise); how easy it was to find their way around using the signs provided (e.g. symbols and written words on signs); and finally, the quality of the interaction they received from staff members (e.g. kindness of staff and willingness to provide help).

Dementia friendly is just friendly for all

While they struggled to find information, participants engaged enthusiastically in visiting local places and ‘rating’ them for the second part of E2. During their time they described several instances of feeling ignored or devalued by staff when in certain stores. For example, Nicole noted staff at a shop *“didn’t come over and offer help and we were walking around like lost souls ... we weren’t welcomed”*, and Shelley felt that the cashier in the store she visited *“was miserable”*. They found this lack of attention from staff made places feel *“hostile”* (Nicole). Within the train station they felt staff *“didn’t seem very friendly”* (Nicole) and were unapproachable, which might make buying a ticket from a machine particularly difficult. They compared this experience to buying a bus ticket *“you could only buy tickets from the machines, whereas on a bus you’ve obviously got a driver who could accommodate and help”* (Nicole). However, they appreciated how friendly staff within a sports store smiled and joked with them when playing with the equipment, and felt they would extend this good nature were someone with dementia to make a mistake: *“if something was to happen that you didn’t mean to do, then they might not take it too harshly, so if you dropped something they wouldn’t tell you off”* (Nicole). In addition, the youths reflected on issues within the places themselves that could cause issues for someone with dementia. Loud music, multiple offers being advertised within the same vicinity and bright lights were seen to be negatives. They also *“found it really cluttered, there were different things everywhere so it was a bit confusing”* (Shelley), while changes in flooring designs *“might give the illusion of a step”* (Simon).

This activity provided the youths with a brief insight into the possible experiences that people with dementia might face on a day to day basis: *“I’ve never even thought about how a place*

could be dementia friendly and the impact that could have on someone but it was very interesting." (Simon). Significantly, what came through here was *"dementia friendly just means friendly for anyone"* (Simon), in regards to the sense that in some places they were ignored or poorly served because they were *"youths"*. In this sense *Friendly* allowed them to connect with people with dementia in a new way, by helping them consider how they might associate their own experiences of exclusion with their loved ones'.

Finding ways in to conversation

The participants initially struggled to enquire into Agnes' situation in E3. The scenario gave only a small glimpse into her life. It inferred that Agnes had someone called "Fred" coming along to visit; but it was ambiguous who he was, whether he was still alive, and when he'd arrive. Nicole and Shelly, for example, both wished to avoid talking about Fred: *"if you start prompting too much about Fred, if he isn't around any longer how do you handle that if she isn't aware that he's not there"* (Nicole); *"or if she suddenly remembered that he'd died and it affected her"* (Shelley). In an attempt to avoid sensitive conversation points, participants focused instead on generating 'tickets' that would speak to things that she might enjoy engaging with; *"we wanted to build up a trust with her, so she felt that she could share her memories with us"* (Nicole). Leslie noted the importance of Agnes singing along to a musical in the scenario: *"We'd share with her the musicals that we liked and stuff like that"* (Leslie). Shelly and Nicole also observed this, and searched for and gathered snippets of media related to musicals to share with Agnes: *"we've saved a few photos from the most famous musicals and then we went and looked at the actors that were in them, and saved a few photos of them to see if she recognized them or knew any other films that they were in"* (Shelley). Simon and Leslie also approached the activity by thinking about when she was born and key periods in her life: *"we looked at the years she was remembering, so 1954-1955, the films that were playing around that time and the famous actors and actresses"* (Simon).

While this activity allowed the youths to think about how to initiate and support meaningful conversations, it was clear further support would be required to make the realization of this concept successful. We role played the scenario again, asking them to use their tickets to initiate a second conversation with the character (played by a researcher). There were several instances where participants became uncomfortable; not quite sure how to manage digressions from the topic they had introduced or unresponsive instances (typical of many interactions with a person with dementia). Some became over-insistent, asking multiple questions related to their ticket of choice. This highlighted the need for careful scaffolding of such conversational support, so that such communication breakdowns can be repaired as they occur, or avoided in the first place.

DISCUSSION

We have described a co-design enquiry with 14 youths to explore their experiences of dementia and how we might use technology to support them in engaging with the condition.

As mentioned, there are approximately 250,000 young people who currently provide care to some degree for people with dementia [44], yet there has been only limited research which has focused on their needs. Our study contributes a deeper understanding around the multifaceted experiences of dementia from a youth perspective; their desire to be more involved within family care relationships and how their information needs are currently not being met. In the following, we offer a set of considerations for future research exploring the development of digital tools and platforms to support youths in their relationships with people with dementia. Whilst we only worked with a small group, the insights provided within this work provide a useful first step towards inciting exploration into this complex design space.

Engaging youths in discussing dementia

We noted many complexities within our design process surrounding engaging youths in discussions of dementia. While participants were willing to open up and share their knowledge and experience within the confines of the research, there was a certain level of discomfort expressed in later stages around sharing very personal experiences. This finding corresponds with previous literature surrounding social support networks, which states that whilst strangers and extended social networks are seen as useful for providing informational support, seeking behaviors surrounding emotional support are reserved for close family and friends [50]. In addition it is worth noting how youths' social identity formation could potentially have a role in this unwillingness to open up; being at a developmental stage of life where social and personal identities are being carefully constructing [13]. The process of describing negative experiences of dementia with friends, a condition known to carry stigma [6], could somewhat hinder their self presentation of themselves as 'cool' [16]. However, more positively, the youths expressed a great desire to promote and advocate around dementia, filling gaps left by unintelligible, generic information. Reflecting on these points, an idea like the *Friendly* app could provide a way for youths to begin thinking about and discussing dementia more openly. By asking people within their existing social networks to engage with *Friendly* and think about what makes a place suitable for someone with dementia, there is a possibility that they could engage a wider range of people in discussions around the condition, putting the external loci of attention on the surroundings and not their personal experiences per say.

Valuing youths within the family unit

One recurring issue throughout our study was the roles of youths in the ongoing care relationships within the family unit. Many of the youths felt 'left out' and somewhat sheltered by their families in relation to discussions of dementia and the changes that were happening with their loved one. For some, it was a subtle alteration in the way their family members treated the person with dementia; a gradual withdrawal of trust that saw them being restricted in their once prominent roles as caregivers for children. For others it was exposure to the family's frustrations and lack of

understanding around the condition that was upsetting. It became clear that the youths wanted to feel supported as valuable actors within the care relationships, whether this be by gaining knowledge and understanding about the condition, to support their inclusion in ongoing conversations, or effective communication skills to support their interactions.

This finding highlights the need for future tools which support the young person's role in the family unit. This involves not seeing them as a separate user group, per say, but finding ways to link the family together around the topic of dementia and support them as a whole. Previous research with youths has focused on supporting their individual identities and the social peer relationships which occur around them, often motivated by the position that youths should be supported in asserting their independence [32]. In our case however there is a need to consider the familial relationships around the youth. In this sense our ticket-to-talk idea, which admittedly was narrowly focused on the youths themselves within the workshop, could be used as a tool to support and structure family interactions. It has the potential to support the creation of shared resources, information and shared learning about the condition, and the building of skills to facilitate interaction with the person with dementia. Throughout our study, the youths brought a level of positivity in their discussions of dementia that could be harnessed within the family. Furthermore, this could lead to the development of novel digital tools which move beyond the functional care aspects of dementia, which have more commonly been focused on in past literature working with adult caregivers [e.g. 26,28,39].

Supporting effective communication

Another issue throughout the study related to finding ways to support conversation, by helping the youths connect with their grandparents in new and meaningful ways. This echoes findings from Strom and Strom [42], who described how many grandchildren report that they do not have a close relationship with the grandparent, despite the grandparents indicating the contrary. The authors suggest that this might be due to contrasting sharing practices among the generations, with youths being more open to sharing their feelings, thoughts and emotions, and older adults remaining guarded in their sharing practices. In this sense, the grandchild is used to being the 'topic' of conversation, with themes of discussion focusing on their lives, achievements and futures. However, with dementia, there is often a need for conversational partners to have a level of pre-existing contextual understanding about the person and their past lives, in order to find 'a way in' to conversation [49], which can be challenging for youths.

In this sense, our *Ticket-to-Talk* idea opened the potential for the young people to learn about and connect with older loved ones in new and interesting ways, using a range of media to do so. However, we found that they displayed a level of uncertainty in relation to managing potentially complex

situations (such as the person with dementia displaying issues with topic maintenance). Whilst there is potential for future technologies to provide in-situ support during times that communication breakdowns occur, previous research suggests that these are not always effective and can instead cause additional stress on the conversational partner [21]. In this sense, it is important that future technologies not only facilitate the curation of media and scaffolding of conversation, but also provide a way for youths to shape their practical communication skills. This might be through the provision of practical tips and strategies (e.g. similar to that provided by [53]), or by providing them with a space to reflect on their interactions and the successes and challenges they have faced. Previous work has explored the benefits of collaborative reflection within interpersonal communication in a counseling context [40]. Whilst this is obviously presented within a different context to our work, there is potential for future systems to provide a space for scaffolding collaborative reflection around successful communication strategies, between youths and their family members.

CONCLUSIONS AND FUTURE WORK

Through this study we have offered a deepened understanding of the specific needs and values of youths within the context of engaging with dementia. Our study has reinforced the central role that the initiation and maintenance of conversation, supportive communicative environments, and the recognition of individual personhood, have in supporting intergenerational contact between young people and their loved ones with dementia. The design concepts we created were not intended to be finalized solutions, rather, they served as a tool to facilitate discussion. Future research is required to further scope the design space around digital systems to support youths in connecting with loved ones, through facilitating the initiation and maintenance of meaningful interactions, whilst being appreciative of the complex family relationships that surround youths and people with dementia. There is great potential for future systems to scaffold information and support sharing practices among both peers and individual families.

ACKNOWLEDGEMENTS

This work was funded by the EPSRC Digital Economy Research Centre (EP/M023001/1) and the ESRC-IAA 'Co-production of dementia-care communications technology' project. Data supporting this publication is available under an 'Open Data Commons Open Database License' and is available at: <http://dx.doi.org/10.17634/141304-7>. Please contact Newcastle University Research Data Service at rdm@ncl.ac.uk for access instructions. We give special thanks to Miriam Sturdee for designing figure 1.

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